Iowa Autism Council Meeting

January 12, 2011 meeting notes taken by Sue Baker and Beth Buehler-Sapp

<u>Present</u>: Sue Baker, Beth Buehler-Sapp, Josh Cobbs, Danielle Sharpe, Katherine Byers, Marty Ikeda, Kenda Jochimsen, Karn Johansen, Linda Louko, Toni Merfeld, Steve Muller, Jim Mumford, Susan Smith, Barbara Stineman, Chuck Wadle, Debra Waldron, Casey (Patrick) Westhoff, Monica Ryan-Rausch (sub for Keith Gatrost), and Theresa Armstrong (sub for Jeanne Nesbit).

<u>Absent</u>: Jeanne Prickett, Keith Gatrost, Becky Harker, Laura Larkin, Jeanne Nesbit, and Pamela Parker.

Guests: Dr. Bob Stensrud, Mike Couvillion, & Matt Bruinekool from Drake University. David Tilly, Andrea Matheson, and Stacy Volmer from Heartland AEA. Roxanne Cummings from Waukee CSD.

Acknowledgements:

Steve Muller of the Homestead was featured in an article today in the Des Moines register interviewing him regarding the opening of the new clinic opening there featuring child/youth services.

Danielle Sharpe recently had an interview on WHO radio station regarding Autism Insurance. Jim Mumford acknowledged that the new insurance coverage for autistic services is now in place and should be working. Typically, Wellmark processes claims within a 30 day turnaround timeframe.

Announcements:

There will be an Autism Awareness/Advocacy Event at the State Capitol coming up on Thursday, March 24th from 8am-11am.

Aspen Athletic Club in Des Moines has contacted Josh and other council members to let us know that they would be offering a Social Skills/Fitness group for individuals with autism 5-18 years in Des Moines. Josh is not sure about the program and will be checking into this further.

Autism Services Survey

The survey is intended to identify the process backup to the IEP process.

<u>Survey Update:</u> Dr. Bob Stensrud from Drake University presented to the council to update them on the survey creation and IRB process so far. The four main pieces of information to be obtained through the survey process are as follows:

- 1. Number of Adults/Kids in Iowa with Autism?
- 2. What services are being provided/to how many persons?
- 3. Are recipients satisfied with the services they are receiving?
- 4. Identification process How do you know your child has Autism? (This is necessary to sort out inappropriate identifications) i.e., Psychiatrist/Psychologist diagnosed vs. my grandmother says my dad had it and I have it, etc.

Once the survey creation process is finished an IRB (Institutional Review Board) process will be conducted to approve finalization.

Josh mentioned that Sue Baker, Sean Casey, and Toni Merfeld from the Iowa Department of Education have been working with Bob Stensrud, Matt Bruinekool, & Mike Couvillion on the survey's creation. Two major factors are as follows:

- 1. Confidentiality is a big issue.
- 2. Survey length should only encompass 10-20 minutes.

In the AEA survey, teachers, OT staff, and speech professionals make up the majority of service providers. Parent survey targets parents of individuals with ASD.

Katie Byers suggested that multiple responses to an answer could be chosen/relevant. Katie also brought up that some participants might not feel comfortable with identification by name and questioned whether using initials for instance would be an effective replacement.

<u>Identification Issues</u>: Sean Casey stated that identification by name is necessary. In order to solicit valid data and provide services accurately specific identification of an individual is necessary.

Dr. Stensrud stated that a school district can say "We have no children with autism so we don't have to provide any services." Therefore, gathering personal data is important. Josh stated that teachers, schools, and the Dept. of Education will not be seeing the data.

An informed consent signed authorization form will be part of the IRB process. This is an important part of how we use and safeguard information. Having the necessary information will enable the system to better provide services. Name identification issue is usually the biggest concern. A 'letter' will explain the data, what and how long it is kept, and other issues of informed consent.

Identification of provider is also essential component as a response from the parent survey as this is needed to get a good measure to tie services to people receiving services, both by number by disability.

Sean Casey reminded the group that this survey is really the 1st domino in a series, therefore the 1st of multiple surveys just like the 1st of multiple dominos to create a path.

Dr. Stensrud stated that he and Matt have done a lot of research communication with vocational rehabilitation and employment training due to work contracted by Kenda.

There will be definition boxes as well. Providing drop down boxes will help survey responders. For type of service for example, under behavioral services if you choose PBIS, a whole list of specifics comes up.

Katie Byers asked the question, "Are we wanting age & gender information?" Sean Casey stated that this information is needed to compare services. Sue offered ideas of determining our state ratio of boys to girls could be an important factor.

Educational Accommodations question: Questions were posed in relation to question #6 regarding Educational Accommodations and if that is the most appropriate language for the responses below. A parent may see several choices that he/she doesn't have knowledge of what they entail. i.e., 504 Plan, IEP, etc. Under question #6, IFSP (Individualized Family Service Plan) will be added as an additional response option. Also, multiple pertinent answers chosen/dual selection is accepted.

Chuck Wadle posed the question, "Does none of the above, i.e., something not being a selection option mean general education?" In theory, no option chosen would indicate general education to many, so general education will be added as a choice on question #6.

In relation to question #6, it could also be rephrased "What other services/programs does your child receive/participate in?" A descriptor pop-up box will come up to provide definition of the terminology used. An additional option rephrasing for question #6 is: "Does your child receive any of the following?"

Sue Baker brought up the example of how this would relate to for example, a private catholic school. It would not because they are not under the same legal obligation as public schools to provide identified services.

Sean theorized that this first survey will find out what we don't know and should have asked. Steve inquired, "Do families consider SCL (Supported Community Living) and respite components to have a significant impact?" and thus should be listed? Sean stated he "thinks parents probably will feel these are an important component but that the DE has no way of regulating these particular services". Others indicated SCL is not used for academic but yes some educational implications. Send feedback to Josh by Wednesday of next week regarding keeping the focus on schools and related services or not.

<u>Summary results:</u> Chuck Wadle asked if folks who complete the survey will receive summary feedback. Dr. Stenrud's answer was "That will be a required IRB component." Josh stated that if anyone has issues with categories or things listed that you need to e-mail these to Danielle within 1 week, or by 1-19-11. Danielle, when finalized with the next draft will e-mail the final version to Dr. Stensrud at Drake. An overall satisfaction summary will be provided.

<u>Communication item:</u> Karn Johansen asked for a clarified definition of what is meant under the communication heading with respect to what parents can request. Danielle stated that if desired a parent could request a daily communication log or comments to be completed by the teacher.

Kenda Jochimsen cautioned about asking for more frequent communication if you're satisfied with what you're already getting weekly or bi-weekly. If you're satisfied with what you're already getting then this could be not needed and would substantially increase the communication response demand.

Matt from Drake stated that as a group of people the goal is to help and inform and therefore we could be composing a group to do so.

For comments, questions, & concerns regarding this Josh will send out an e-mail with a link provided to the council by the end of the day tomorrow.

<u>Updates:</u> Josh, Danielle, Sue, Dr, Stensrud, Sean, and Toni will review any suggested changes as received and any needed changes will be made.

Access to parents: ASI will announce the link to Drake University for the survey in their newsletters, the walk list from Autism Speaks will be used, Parent Educator Connection can put an advertisement in their newsletters with the link, ARC can be a source, and there may be options for press releases (further discussion at Iowa Autism Council meetings). A date will be provided so that survey responses can be gathered by a specific date. AEA's will be approached to see if they can send it out as well.

<u>Personal identifier of diagnosis</u>: Linda Louko asked the question, about the diagnosis and what agency/facility is determined with the ability to diagnose. There is a significant disparity between a psychiatrist or medical practitioner making an identification of a disorder or a grandmother, mother, etc reporting that an individual has Autism. Therefore when the question is asked "Does your child have an ASD (Autism Spectrum Disorder), the follow-up question will be "How was that determined?"

<u>Data required to match IMS</u>: Marty Ikeda stated that a child's name, birthdate, and school need to be supplied in order to match/align it with the IMS (Iowa Medicaid System) data.

Sean says this is essential because you could have multiple respondents completing surveys with regard to the same child, i.e., mother, father, grandparent for example. By having solid identifiers we can identify duplicate responses with regard to the same child. Ultimately, folks will still have the option not to include specific identifier information in regard to the child.

The council will write information to the IRBs as to why we want data and Dept. of Education will only receive macro response data. For example this would enable the Dept. of Education to match the number of children with Autism identified in the Sioux City CSD with the number of services being provided and to how many children in the Sioux City CSD.

<u>Additional sources:</u> Sean asked Theresa Armstrong (sub for Jeanne Nesbit) if the IME (Iowa Medicaid Enterprise) sends out an electronic newsletter.

<u>Access to parents continued</u>: Marty informed the council that the AEA's are not required to send out this survey but that he hopes the AEA's will work with the Department of Education on this process.

Katie Byers asked the question, "Did the sub-committee consider asking only the page 1 questions for the initial surveying process and making pages 2 and 3 a follow-up survey?"

Josh responded "No, we want the survey to gather more information other than just the demographics."

Sean Casey related to the group that the survey really isn't very long as surveys go and that it is a proven conclusion that any length of survey can be ignored.

Deb Waldron asked if there is an age component for the survey's audience and Josh responded that yes, just like with the educational program requirements, 3-21 is the relevant age.

The survey request response time will be 2 weeks for participants to get it completed and returned and which would mean survey results to be back by the end of April.

<u>Summary to the Council</u>: Linda Louko asked if once the survey is finalized, will the council see it in its final form. Josh replied that yes, the council will receive a copy of the completed survey once it is done.

Josh stated that there will be a vote on the questions that we ask as a council.

Josh reminded council members of the appropriate ways to support communication of something when done by a council member. As a council, a letter of support of something

could be done. However, Council members cannot make contact to entities and support their views/requests as those of the council. This must be done by individuals as individuals, i.e., Josh Cobbs, Sioux City resident, father of a child with Autism (not Josh Cobbs, IAC Chair).

Combating Autism Authorization: Next, the council members reviewed the Summary of the Combating Autism Reauthorization Act (CARA) (S. 4044) as the handout and link to the 245 page authorization was provided by Josh. Linda Louko posed the question, "Does it matter that this was sponsored by Chris Dodd and that he is no longer in office? Josh responded that no, while Chris Dodd was the incumbent who has been replaced by Senator Robert Menendez, this was originally co-sponsored by Senator Menendez and should have the same backing expected and this clearly shows Senatorial support.

The Council can decide to write a letter of support or not. We will not be using advocacy strategies nor calling your legislature language, but we can alert others to this content. This will be discussed at our next meeting.

<u>Survey results impact on services</u>: Kenda stated that in summary, the survey results would reflect how many services and which services individuals are receiving. Sean related that based on the feedback from parents you can deduce which services folks are valuing. All behavioral services listed up through the daily living section are research based. The practices listed under Related Services are not defined as evidence based practices.

<u>Communication questions:</u> Susan Smith stated that a students' modality of communicating is way less important than functional communication, i.e., verbal vs. signs/pictures. Sue Baker reiterated that it's important to know that a child has a functional communication system. Susan asked if vocal behavior should be added. Discussion continued with Danielle's group to finalize the category and share it with the survey subcommittee.

Sean related that communication skills are an important factor. Question: How satisfied are you with the communication in your child's school? It helps to get both sides of the information. Form a list of the things that parents want which are evidence based. Form a list of what parent consider beneficial but are not evidence based practices. How satisfied are you with the quality of services?

Presentation of survey results by Waukee CSD and AEA 11 staff
Waukee Autism & Behavior Study powerpoint
Roxanne Cummings, Director of Special Education Services, Waukee CSD
David Tilly, Andrea Matheson and Stacy Volmer, from Heartland AEA

David introduced the survey to document effective services with the target of program improvement. Roxanne Cummings talked about providing a clear rationale for data collection and analysis processes used, implications for their students, and to think about program enhancements. They targeted ASD students and those with challenging behavior. Their needs assessment became a program evaluation.

Waukee CSD currently has a total of 6680 students, of these 541 students quality for special education services by the following breakdown:

- 341 receive level 1 services
- 153 receive level 2 services
- 47 receive level 3 services

Waukee's framework for meeting the needs of all students is based on the following:

- Critical IEP Components in place
- Progress Monitoring
- Data used for Decision Making
- Outside Resources
- Family Engagement

For the process of the study they used the following:

PBIS Implementation Data

On-Line survey Data

Reviewed IEP's (Individualized Education Plan) students had to have been on an IEP for at least 3 months (32 with autism)

Reviewed FBA's and BIP's (Functional Behavior Assessment) and Behavior Intervention Plan

They also determined that by using this format they became skilled at identifying and addressing many behavioral concerns within the general education programming. General education teachers indicated a need for more training & time to support implementing BIPs.

Some staff indicated that implementing BIP's can be stressful but that if they had the support & skills needed for implementation that BIP's are in the best interest of kids.

Students were 3 times more likely to be making progress if they had a BIP versus a 50/50 ratio for students without a BIP.

Intensive File Reviews (IFRs) were completed on 18 student files. Within these 18 students files services received ranged from 9-300 minutes of specifically designated instruction.

Many questions about their project were shared to the Council in the format of question then results during the powerpoint presentation. These questions included:

- the extent of the data collected and used in each school to drive decision making about student behavior,
- information about the range of supports available to meet behavioral needs,
- what elements of the BIP fit in the features of the school,
- are students making progress on social behavior and academic goals,
- is programming for ASD individualized and related to evidence based practices,
- are parents involved,
- are LEA school supports involved,
- are outside agencies involved in the cases.

The handout of the Executive Summary of Waukee Community School District January 2011 summarized the positive key findings about the core cycle, supplemental and intensive cycle and intensive cycle data, General Education findings, and special education findings. They document where programming is strong and provided a series of potential targets where programming can be improved. Team members collecting and analyzing the data would look forward to additional conversations and action planning around the study findings.

Kenda asked, "Are you able to pull that data out for kids in Transition? Haven't yet.

Future goals: Expand the range of general education supports available.

Professional Development for Decision Making
Coaching support for IEP Development

Professional Development regarding Autism NAC comp & documentation Progress Monitoring & IDM High Quality FBA's & BIP's

Feedback from Council: Did you include associates responding to the survey?

Josh – Did you match this data with parent perception? Not at this point yet.

Waukee CSD is going to meet with the Special Education Administrators at the end of this month.

Kenda said Thanks and Kudos to Waukee and Heartland AEA 11 for doing this survey whose outcomes appear to benefit all student and some significantly. If data is further refined, the Council would invite this group back for further sharing.

A question was asked about the Social Economic Class of the areas: maybe 8% are free or reduced lunch. A question was asked about the percent of outside evaluations/consultation and the to and from communication to the school for further clarification.

Insurance Discussion: The notice of intended action (rules guiding the mandate that was passed) was provided to Council members. The council wants to know if Board Certified Behavior Analysts, BCBA's, are recognized by Wellmark as treating professionals. Jim Mumford indicated that it is based on the new Wellmark coverage just approved for state employees that BCBA's are eligible as service providers. Wellmark is working on this, codewise, to get reimbursements. February 17th there will be a public meeting at which time the new insurance coverage can be talked about more and questions answered. As this time legislative code issues are being addressed so the process can operate more effectively. ICD9 coding is often an issue for coverage. The question was posed if providers need to be living in Iowa.

Sean Casey brought up the example that in some states the insurance regulation laws mandate that a provider such as a BCBA must be providing services within the state and not from out of state. Sean was speaking for example about Pennsylvania where he previously practiced and this is the regulation. Sean can provide the Pennsylvania website which provides this information to anyone who is interested.

Susan Smith agrees with Sean's information because she is aware of situations where an out-of-state provider was required to come in state to be eligible to provide covered services for patients. Susan volunteered to check into this further regarding what the State of Iowa's regulations are that pertain to providers of services and residence requirements.

Josh suggested that a series of Frequently Asked Questions, FAQ's, need to be developed in regard to the new insurance facts. Chuck Wadle made a motion for a sub-committee to be formed to develop FAQ's. Casey Westoff seconded the motion. Josh Cobbs and Susan Smith volunteered to work together and develop the FAQ's. Jim Mumford and Angela from his office will review the council's FAQ's once they are developed. Indiana has a model that could be used as a guideline.

Sue Baker posed the question, "How do we as a group, monitor who is using these services?

Chuck Wadle responded that the insurance companies are not under any mandate to release that information. An informal survey is possible to ask: Are you a state employee? Was the service effective? We may be able to get aggregated numbers and costs.

IAC Final Recommendations from 2010: Josh informed the Council that IAC's Final Recommendations document was reviewed by the Department of Education and approved to be sent to the legislature and this has been done electronically. Josh stated that he will e-mail this final document out to the council members.

Josh - Thanks to Beth and the other DE folks involved for getting the final recommendations done and disseminated and the voting recorded. If anyone wants a copy, Beth has the voting record spreadsheet and can provide this to any council members upon request.

<u>IAC Website and Job Fair:</u> There was brief discussion regarding the website and job fair symposium. Josh said the current plan is to have 1 big job symposium in Des Moines and down the road possibly expand from that.

She stated that there is a gap between graduation and getting job training for disabled individuals. People need to be qualified for jobs and typically with the onset of an economic downturn jobs that employ the disabled are some of the first to go. Issues are not only funding streams, but job matching issues, staff development, etc.

Josh, Steve, Sue, and Frank Forcucci have volunteered to work on the Iowa Autism Council website. Susan, Kenda has volunteered Ruth, and Casey and will work on the job fair symposium piece.

It was motioned to adjourn the meeting and seconded.